

Thoughts on the Action Committees of The American Society of Human Genetics

Stanley M. Gartler

Departments of Medicine and Genetics and the Center for Inherited Diseases, University of Washington, Seattle

During this year, as president of The American Society of Human Genetics (ASHG), I have been struck by the extensive role played by our action committees: Social Issues, Genetic Services, Information and Education, and Public Policy. The initial reason for the growing prominence of our action committees is the spectacular technological success human genetics has enjoyed in improving genetic prognosis. These technological advances have had a significant impact on reproductive behavior and in turn have engendered many social reactions.

With this rapid advancement in medical genetics, the membership of ASHG has increased and diversified considerably. Twenty-five years ago the society consisted largely of clinical and laboratory scientists, with a relatively small percentage of the membership involved exclusively in counseling activities. Today we have a large number of members who function exclusively in the delivery of genetic services.

Finally, these committees function because ASHG has the funds for their support, and the funds are available because ASHG has been successful as a scientific society. These activities have added an exciting new dimension to our society and have broadened its base. On the other hand, some of these actions are more political than scientific and may not be entirely appropriate for what is basically a scientific society.

The prime aim of any scientific society such as ours is the promotion of the gathering and exchange of knowledge in the field of that society, human genetics in our case. There are two vehicles for this purpose:

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Address for correspondence: Stanley M. Gartler, Departments of Medicine and Genetics and the Center for Inherited Diseases, University of Washington, Seattle, WA 98195.

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the society journal and the annual meeting. We do both of these reporting functions very well, and consequently we are able to support our extensive committee structure.

Our action committees are involved in a number of varied functions, such as acting as judges in science fairs, organizing symposia for other societies, putting out position papers on α -fetoprotein screening and DNA banking, and trying to influence various levels of state and federal government on issues of concern to our society. Projects such as position papers on α -fetoprotein screening and DNA banking are based directly on the scientific expertise of our membership and seem completely justifiable endeavors for our society. The α -fetoprotein position paper took several years to reach fruition, reflecting the diversity of expert opinion in any such complex area and the generally conservative process of crafting a scientifically based document. Drafts of this paper were widely circulated before a final form was approved. The same process is being followed for the DNA banking paper.

On the other hand, when we as a society write to senators, congressmen, or governors, trying to influence their vote on some matter of concern to us, we do so on the basis of the opinion of a very small subset of the society, the Public Policy Committee. I agree that if we want to influence the outcome of a particular vote it would be impractical—if not impossible in many instances—to first obtain the approval of the membership. In some cases, at least, timing makes such contact impossible. However, we could act in such matters by having the relevant committee alert the membership to write as individuals on particular issues. We do this also; but there is the feeling that sending a letter representing the society as a whole has a special impact, and I suspect that this feeling is correct.

One public policy action that we took this year

involved a letter to Governor Thompson of Illinois, urging him to veto a modification of a right-of-conscience act. This bill, if passed into law, would have permitted a physician to not counsel a patient regarding the possibility of abortion if abortion was contrary to the physician's religious or moral beliefs. Our letter, drafted primarily by Drs. E. Short and L. Fleisher and sent over my signature, was one I had no difficulty in signing. The bill, which was finally vetoed, would have had the effect of restricting access to information, limiting free choice, and essentially permitting one person to impose his or her religious or moral beliefs on another person. However, our letter and stand were basically political. With few changes our letter could have been used in other situations in which access to information and free choice were threatened. We were not really using the scientific expertise of the society in arriving at our position. In signing this letter I felt confident that the majority of our members would feel comfortable with its contents, though I was not at all certain that this same majority would want the society to speak for them on such a matter. At any rate I did not feel there was any danger of divisiveness arising as a result of this action. Could one conceive of the Public Policy Committee taking the opposite stance, favoring the Illinois bill? Such an action would have shaken the society to its foundations.

It is of some interest to note that our parent or sister society, the Genetics Society of America (GSA), has steadfastly refused over the years to take political stands as a society. During the 1940s a move was initiated to have the GSA take an official position on Lysenkoism. Here was a case of distortion of genetic facts, and yet the GSA would not take a societal position. Later, during the early 1970s, when the relationship between race and IQ was being heatedly

discussed, an attempt was made to have GSA take an official stand on this issue; but again the society refused, and in the end many members, as individuals, signed a letter criticizing the race-IQ proposition.

ASHG is different in many ways from GSA. GSA members are diversified along organismal lines but are primarily involved in basic research. We are a very focused group as far as organism is concerned but very diversified as to activities. However, most of us, regardless of whether we are involved in cytogenetics, counseling, linkage, or gene cloning, are concerned in one way or another with the application of our findings to the human condition. That is a bond that I believe helps maintain the basic structure of our society in spite of our diversity. Our applied activities also make it difficult to remain aloof from public policy.

However, like GSA, we are still basically a scientific society: our "purpose is to encourage research in human genetics and to bring into closer association investigators in Canada, Mexico, and the United States who are interested in human genetic research and related problems." All of our activities as a society, including funding, rest on a research base. We are also more international than our stated purpose indicates, and certainly we must keep that in mind when taking local political stands. ASHG has grown into a complex and lively organization since its formation in 1948, and the action committees have become an integral part of our structure. Actions that are broadly based in the membership and scientific expertise of the society can only add to its attractiveness. Actions that are narrowly based in membership and largely political in nature can be equally attractive—but also divisive. In the latter case, it behooves us to be as cautious as possible before taking a largely political stand.